

September 18, 2006

Dear Chairman Barton:

We write to offer our enthusiastic support and profound gratitude for your proposed "National Institutes of Health Reform Act of 2006".

As representatives of the shockingly large and disturbingly growing community of American families afflicted by autism, we cannot commend you enough for your efforts to improve the effectiveness of the significant investment our nation's taxpayers are making in the National Institutes of Health.

The NIH is truly one of the crown jewels of the federal government. There is no higher purpose, nor potentially greater "rate of return" on public dollars than the protection of public health. For these reasons, however, oversight and policy guidance of the NIH by the Congress is enormously important and the experience of the autism community with the NIH is powerful evidence of the need for the reforms you have proposed.

As you know, autism spectrum disorders ("ASD") now afflict 1 in 166 American children - 67 new cases per day, 24,500 per year, are being diagnosed. It has become by far the most prevalent developmental disorder and touches far more children than other common and serious ailments such as childhood cancer and juvenile diabetes. A recent Harvard study indicated economic costs to the nation from ASD at \$90 billion annually, and climbing.

Many autistic children will never speak and will need care, essentially 24 hours a day, from the time they are 2 years old until the end of a normal life span. It bankrupts and ruins the marriages of many of their parents, and breaks the hearts of the millions of Americans who know and love these children.

Instead of the urgency which would seem the obvious and appropriate response to this epidemic, the NIH has responded slowly over the last decade to the growing public health crisis of autism. And the progress which has been made on how the agency handles autism has mostly been the result of parental advocacy and Congressional direction, through the Children's Health Act of 2000.

We respect the work of many fine public servants at the NIH and do not believe that the record of the NIH on autism is a result of malevolence. We believe, instead, that your bill is right on target in identifying and seeking to redress structural flaws in the bureaucratic arrangement and functioning of the NIH which produce poor results on autism.

In particular, empowering the Director of the NIH and creating a common fund to promote trans-NIH research activities are absolutely essential reforms for the agency to be effective with respect to autism and the many other ailments which cannot and should

not be locked within the “silo” of any particular component institute of the NIH. Likewise, agency-wide reporting, a process for “scientific management review” and a new emphasis on “high risk, high reward” research will all benefit the autism community and all Americans.

Once again, we commend you for your effort to maximize the impact of the NIH on the health of America.

Cure Autism Now Foundation  
Autism Speaks  
US Autism and Asperger Association  
Autism One  
The Deirdre Imus Environmental Center for Pediatric Oncology  
First Signs  
Generation Rescue  
Southwest Autism Research & Resource Center  
COSAC  
Unlocking Autism  
Organization for Autism Research  
Autism Society of America  
National Autism Association

cc: The Honorable John D. Dingell